Nursing Best Practices in the Community: Recognizing Dementia in People with Intellectual and Developmental Disabilities and Planning Appropriate Health Services

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Objectives: Upon completion of this course, the nurse will:

1. Use a dementia screen for adults with intellectual disabilities.
2. Recognize the differential diagnosis process as applied to the dementia diagnosis.
3. Describe elements of environmental changes that support people with the diagnosis of dementia.

4 Most Important Facts About Dementia

1. "A loss of cognitive (thought) function **severe enough to interfere with daily functioning."**

2. The term "dementia" describes a group of **symptoms**.
   a. It is **not a specific disease**!
   b. "The doctor said my son has dementia…thank goodness he doesn't have Alzheimer's!"

3. The condition we refer to as dementia may be caused by many things.
   a. Some may be **treatable** (Ex. Dehydration, B12 deficiency)
   b. Others are **irreversible** (Ex. Alzheimer's, Vascular, Lewy body).

4. Dementia is **NOT part of normal aging**.

Irreversible Dementias

The symptoms we call "dementia" can have many different causes.

Alzheimer's disease is the most common.

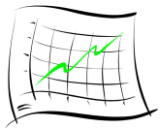
Image: Dementia Forward

Risk of Dementia in ID

Most adults with ID are typically at no more risk than the general population.

<u>Exception</u>: Adults with Down syndrome are at increased risk!

- Younger (40's and '50's)
- More rapid progression.



Dementia Prevalence: ID vs. DS

Intellectual Disability		Down Syndrome	
Age	Percentage	Age	Percentage
40+	3%	40+	22%
60+	6%	60+	56%
80+	12%		

Matthew P. Janicki and Arthur J. Dalton (2000) Prevalence of Dementia and Impact on Intellectual Disability Services. Mental Retardation: June 2000, Vol. 38, No. 3, pp. 276-288.

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Increased lifespan = Increase in dementia.

What this means for programs:

- Need to raise the "index of suspicion" among staff and families,
- Programs and services need to become "dementia capable,"
- Need to improve:
  - Diagnostic and technical resources,
  - Care management supports (to prolong the "aging in place" of adults affected by dementia).

Warning Signs

These problems must be notable and usually occur in a cluster

Conditions Common to Aging That Can Mimic Dementia

- Dehydration, Malnutrition
- Metabolic Disorders
- Vitamin & Mineral Deficiencies
- Sensory Impairments

Community Care Needs of Adults with ID and Dementia

- Dementia is a condition that impairs an individual's ability to self-direct and be left alone.
- Thus…independent living will not be an option as the disease progresses.
- What will be needed?
  - In home supports (to family caregivers and the person)
  - Advanced planning for alternative care
  - Diagnostic, medical and behavioral health care
  - Support groups for caregivers (family or staff)
  - Dementia capable community housing
  - Day care programs and respite for family caregivers

Aging & DD Services…Build a Bridge

- Community support provider agencies
  - Private/parent based (e.g., Arc chapters)
  - Public – state/local government entities
- Area Agencies on Aging (AAAs)
  - Aging and Disability Resource Centers (ADRCs)
- Alzheimer's Association chapters
  - Other local dementia care groups
- State and local Protection and Advocacy Networks
- Faith-based organizations
- Statewide or Community-based Respite/Caregiver Coalitions

Normal Age-Related Memory Changes vs. Dementia

Typical Aging:	Symptoms of Dementia:
Complains about memory loss but able to provide detailed examples of forgetfulness	May complain of memory loss only if asked; unable to recall specific instances
Occasionally searches for words	Frequent word-finding pauses, substitutions
May have to pause to remember directions, but doesn't get lost in familiar places	Gets lost in familiar places and takes excessive time to return home
Remembers recent important events; conversations are not impaired	Notable decline in memory for recent events and ability to converse
Interpersonal social skills are at the same level as they've always been	Loss of interest in social activities; may behave in socially inappropriate ways

Adapted from: *The American Medical Association*

Differential Diagnosis

Definition: The distinguishing of a disease or condition from others presenting with similar signs and symptoms.

Two Stage Process:
- Establish dementia is present.
- Determine the cause.

Not all dementia is irreversible!

Clinical Features of Various Dementias

Alzheimer Disease	Frontotemporal Dementia	Lewy Body Dementia	Vascular Dementia
Memory, visual-spatial and language disturbances	Personality changes	Visual hallucinations	Abrupt onset
Indifference	Executive dysfunction	Delusions	Stepwise deterioration
Delusions	Disinhibition	Falls	Prominent aphasia
Agitation	Impulsivity	Syncope	Motor dysfunction
Behavioral changes	Progressive loss of speech	Parkinsonism	Mood or behavior changes
		Fluctuating memory	Severe depression symptoms
		Sensitivity to antipsychotic medications	

Although the brain neuropathy will differ, caregivers need to note the nature of the behaviors exhibited.

Why is it Important or Useful to Know Type of Dementia?

Different types of dementia have different characteristics. It can be helpful to know that particular behaviors are part of the disease process and not bad behavior.
- Lewy body – visual hallucinations
- Fronto-temporal – profound personality change, disinhibition

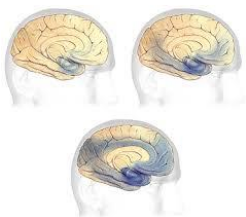
The type of dementia may impact what medications are used.
- Lewy body – sensitivity to certain antipsychotics.
- Fronto-temporal – does not respond to common Alzheimer's medications such as Aricept.

Ensure that treatable causes of the symptoms have been ruled out.

Common Conditions to Rule Out through Differential Diagnosis.

- Stroke
- Side effects of medications ★
- Nutritional deficits and imbalances
- Alcohol and drug abuse
- Hypothyroidism
- Dehydration, malnutrition
- Cardiovascular disease
- Environmental challenges
- Sensory impairments
- Depression
- Lyme disease
- Normal pressure hydrocephalus
- Sleep apnea

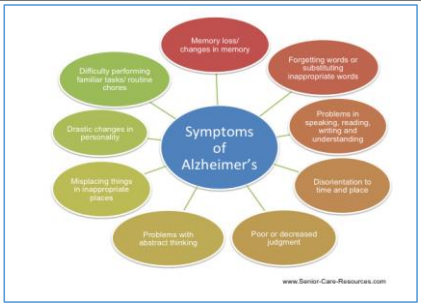
Progression of Alzheimer's Through the Brain



Source: Alzheimer's Association

Dementia Affects All Aspects of Functional Ability

- Memory
- Language skills
- Ability to focus and pay attention
- Reasoning & judgment
- Sensory perception
- Ability to sequence tasks



Stage Related Changes in Alzheimer's

Early Stage	Middle Stage	Late Stage
• Confusion and memory loss • Disorientation in space • Problems with routine tasks • Changes in personality and judgment	• Difficulties with ADLs • Anxiety, paranoia, agitation and other compromising behaviors • Sleep difficulties • Difficulty recognizing familiar people	• Loss of speech • Loss of appetite, weight loss • Loss of bladder and bowel control • Loss of mobility • Total dependence on others • Death

Health Care Advocacy

Health care advocate - a person who is not a health care professional, but can assist a patient in obtaining high-quality health care.

An advocate may be a counselor at a service organization, a relative, or a friend of the patient.

www.communityhealthadvocates.org/advocates-guide/appendix/glossary

Dementia and Health Advocacy

- Dementia-related health advocacy is:
  - Speaking for the adult affected by dementia
  - Looking after their interests during health interviews and visits
  - Ensuring that concurrent conditions are diagnosed and treated
  - Tracking the rate and course of dementia and helping the health practitioner better understand the changes occurring
  - Coordinating care when various providers are involved
  - Arranging for appropriate care and supports

You May be in a Position to be a Health Advocate If:

- You are given the responsibility to look after the welfare of the adults that are in your program, residence, or organizational activity
- You are a care manager
- You work along with health personnel
- You are a relative or family member
- You are a friend or mate
- You are involved in way that the health of adults you work with can be your concern
- You are engaged in some other capacity that gives you access to health practitioners

Importance of Health Care Advocacy

There are often interventions that make a difference in quality of life and health.

Staff and family are the experts about individuals with ID.
- To recognize current changes and symptoms knowing the person across the lifespan is the best resource.

Health care is an art, not a science!

Why is Dementia Health Care Advocacy Needed?

- Unable to "self-advocate."
- 'Ageism' (prejudice or discrimination on the basis of a person's age) by health care providers.
  - Providers may assume that there will be automatic losses and declines in functioning as part of aging.
- "Diagnostic overshadowing."
  - Providers may assume that the diagnosis is dementia, when another issue may be the cause of behavioral changes.

Four Steps of Health Advocacy

4 Steps of Health Care Advocacy

#1. Observe

- Functional and behavioral changes observed are a form of communication.
- Use a screening tool for observation (NTG-EDSD)

Look for changes in the person such as:

- Behavioral
- Personality
- Activity level
- Unintended weight loss or gain (10%)
- Changes in wake/sleep patterns
- Diarrhea/constipation

4 Steps of Health Care Advocacy

#2. Report

- Document observations
- Be accurate and specific
- Report to the right person
- Use correct forms and processes

Important components of reporting:

- Time of the day, who is present, where did it happen?
- How often do you observe this symptom?
- What was happening before? After?
- Making sure there is a system/process for reporting to the right person!

4 Steps of Health Care Advocacy

#3. Prepare for the health care appointment

- Hold a team meeting (residential/family/program/individual advocates) to bring together symptoms observed.
- Prioritize symptoms and concerns to be addressed.
- Prepare a checklist or form for the attending caregiver to bring to the appointment
- Make sure the person who goes to the appointment with the individual is:
  - Included in the team meeting
  - Able to communicate symptoms
  - Has some health care advocacy skills

A bit more on diagnosis.

Proper diagnosis is important to…

- Rule out treatable conditions.
- Receive appropriate treatment and support services.
- Maintain the highest possible quality of life and functioning.

Remember: Rule out possible treatable conditions first.

- Stroke
- Side effects of medications
- Nutritional deficits and imbalances
- Hypothyroidism
- Alcohol and drug abuse
- Dehydration, malnutrition
- Cardiovascular disease
- Environmental challenges
- Sensory impairments
- Depression
- Lyme disease
- Normal pressure hydrocephalus

Factors That Increase the Risk of Side Effects from Medications

- Advancing age
  - Decreased kidney and liver function.
  - Increased potential for side effects.
  - Dosage guidelines developed for younger persons.
- Lifetime use of medications, especially psychotropic.
- Polypharmacy.
- Decreased fluid intake (due to incontinence).

4 Steps of Health Care Advocacy

#4.

Follow-up after the appointment

- Follow-up recommendations with all caregivers
  - Make sure recommendations are understood.
  - Are there any follow-up the questions?
  - Continue observing and reporting.
  - Don't give up!
    - You may have to search out a new provider
    - Be as prepared for the follow-up as for the first appointment

Final Tips for Health Care Advocacy

- Be aware of myths and stereotypes about aging in persons with ID.
- Know the possible side effects and interactions for medications used by the individual.
  - Beers List www.americangeriatrics.org/files/documents/beers/PrintableBeersPocketCard.pdf
  - Physician's Desk Reference www.pdr.net/browse-by-drug-name
- Never assume the changes you see are the result of aging or the disease of Alzheimer's dementia!

Be persistent! Be an advocate!

What to Do When Dementia is Suspected?

- Benefits of a screening instrument - can help to identify early signs of dementia.
- If screening instrument results are positive, refer for assessment.
  - Refer to Agency MD, local MD , psychologist, nurse, other person who may do formal assessment to validate suspicions
- If assessment confirms screening results, refer for diagnostic work-up.
  - Ideally: neurologist, geriatrician, geriatric psychologist

A Screening Tool is not a Diagnostic Instrument.

- **Screen -** an instrument that permits the recording of select data that is associated with a condition or disease.
  - EDSD
- **Diagnostic instrument -** is one that is based on valid measures that are associated with agreement on the presence of a condition.
  - For example, a MRI will show an image of the brain that may show shrinkage and validate suspicions of the presence of Alzheimer's disease

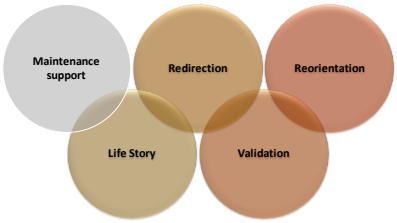
What Does a Diagnosis Mean?

- The person has a name for the problems being experienced.
- Has it changed the person?
  - No. It does, however, give caregivers some comfort in knowing 'why and what'
    - *Why* are the changes occurring?
    - *What* can we expect for the future?
- Allows for important service planning to take places.
- Provides access to helpful resources and organizations

Caring for a person with dementia means we must understand that…

- S/he does not see the world the same way we do.
- What we see as normal can be very confusing and threatening.
- We must enter their reality as they cannot conform to ours.
- Need us to be patient, supportive and understanding.
- WE HAVE TO CHANGE BECAUSE THEY CANNOT.

Key Concepts in Dementia Care



Adapted from *Habilitation Therapy in Dementia Care*. Paul Raia, PhD. 2011.

Key Concept in Dementia Care #1
Maintenance Support

- Generally accepted as the **best practice** in dementia care.
- **Proactive** approach
  - A few minutes of pro-action can eliminate hours of reaction.
- Focus is on **support of remaining abilities**.
  - Respect changing needs of the person
  - Provide meaningful, failure-free activity.
  - Allow the person to do as much as they can for themselves but…be aware that as the disease progresses the need for assistance will increase.
- Can **reduce or eliminate difficult behaviors** at all stages by reducing frustration, boredom, anxiety, fear, etc.
- Can be done in **all settings by all staff**.

Orientation Tips

Whose reality is it?

- A person with dementia can no longer make sense of the present and lost memories of years past will become their new reality and they even may re-live past events.
- To avoid frustration and increasing agitation you must enter their reality. *Don't argue.* This is not lying, it is respecting their reality.

Wouldn't you be upset if someone told you your parent was dead if you were sure they were alive?

Key Concept in Dementia Care #5
Redirection

Distract AND Divert

- Distract and redirect to minimize or avoid outbursts and challenging behaviors.
  - Redirected with gentle distraction or by suggesting a desired activity.
    - Providing food, drink, or rest can be a redirection.
- Smile, use a reassuring tone.

Helpful Hints for Redirecting

- **Body Language:** People with dementia are very adept at picking up on your body language. Smile, try to relax, and be warm and open when redirecting someone with AD.
- **Ask questions.** A good all-purpose phrase is: *"tell me about it."*

Example:

Betty: *"I want to go home!"*

You: *"Tell me about your home. Is it a big house?"* Then gently redirect the conversation away from what is bothering Betty…*"I'm hungry. Betty, would you help me get a snack?"*

Be flexible…
What works today may not tomorrow.

- Solutions that are effective today may need to be modified tomorrow—or may no longer work at all.
- The key to managing difficult behaviors is being creative and flexible in your strategies to address a given issue.

Key Concept in Dementia Care #2
Life Stories

Everyone has a life story that needs to be honored and respected.

- The story is the *essence* of each person and should be documented over the lifespan.
- When a person can no longer tell their own story, activities related to storytelling can still be used to inform caregiving and plan activities.

Body Language

People with dementia are very adept at reading body language:

- Identify yourself.
  - Never assume the person knows who you are.
- Remain patient and calm.
- Don't stand over someone – this can feel intimidating.
  - Try to stay below their eye level.
- Smile!
- If the person is comfortable with body contact patting or holding the person's hand can be reassuring.

4 Communication Strategies

Adapted from: Habilitation Therapy in Dementia Care. Paul Raia, Ph.D., Alzheimer's Association. MA/NH Chapter. 2011.

1. Difficult behaviors cannot be changed with words.

- **Technique:** Change your:
  - approach to the person
  - reaction to the behavior
  - the environment
- Individuals with dementia have impairments in short term memory as well as an inability to learn new information.
- A person with dementia cannot be told to do, or not do, something and be expected to remember.

Communication Strategies
Continued

2. Don't say "No" and NEVER ARGUE!

- You cannot reason with a person who has lost the intellectual ability to process thoughts in a logical and rational manner.
- Arguing will encourage frustration, fear, and anger.
- The goal is not to be correct!
- Remember – the person is experiencing a decline in their reasoning skills at the same time they are experiencing an increase in their emotional reactions.
- Feelings are more important than facts.

Example: Donna tells you she is a movie star. Agree with her. It hurts no one to let them live in a reality that may be more reflective of their dreams than the life they actually lived.

Communication Strategies
Continued

3. It's their reality and you must enter it.

- **Technique:** Validation
- Builds empathy and creates a sense of trust and security that reduces anxiety.
- Enter their reality and reminisce with them.
- Match their emotions.

Example: Tom tells you that his mother was here today (but you know his mother died last year). You say, *"That's wonderful. You must love your mother very much."*

Communication Strategies
Continued

4. Reduce fear by acknowledging underlying emotions.

- As the disease progresses the person loses the ability to express and cope with their fears.
- A person with dementia cannot "self soothe" if their fears become overwhelming.
- Reassure the person and respond to their emotion.

Common Behaviors

Wandering
Repetitive questions
Rummaging, hoarding
Verbal outbursts – yelling, excessive vocalizations, cursing
Physical – hitting, spitting, kicking
Paranoia
Hallucinations
Sleep-wake disorders
Sundowning
Resistance to personal care
Inappropriate sexual expression

Whose Problem is it?

Behaviors can range from the merely frustrating to those that have the potential for serious harm.

Is this behavior just a problem for me?
- Ignore it
- Ex. Mismatched clothes

Does this behavior have the potential for harm to either the individual or to another?

General Tips

- Do not try to reason or argue.
- Stay calm.
- Make sure you have their attention.
- Short sentences with yes/no answers.
- Loud voice can be interpreted as angry.
- Allow time.
- Respond to emotion.
- Distract and redirect.
- Step away and try again in a few minutes.

Take a Step Back

- What exactly are they doing?
- What time of day does it happen?
- Who is present?
- Does it only happen with certain staff, family?
- What happened immediately before? After?
- What has been tried in the past?
- What do you know about this person's life history?

Nursing Process Model

A series of organized steps to accommodating and managing challenging behaviors.

Wandering

Serious safety issue!
70% of people with dementia will wander.

Possible Cause(s):

- May be related to searching for something, escaping from something, reliving the past, confusion in space and time.

Strategy:

- Orienting cues, reduce falls hazards, provide a safe place to wander, camouflage doors, "Dutch" doors, GPS tracking device, plan distractions.
- Make sure the person carries personal identification.
- Understand your state's regulations regarding locked doors, etc.

Repetitive Questions

Causes:

Can be stressful for caregiver but are rarely harmful.

- Inability to retain information (short term memory).
- May be trying to express a specific concern, ask for help, or cope with frustration, anxiety or insecurity.

Strategies:

- Focus on the emotion behind the behavior.
- Stay calm.
- Provide an answer, even if you have to keep repeating.
- Distract.
- Try memory aids.

Rummaging and Hoarding

Causes:

- Unable to remember where they put something.
- Creates a sense of security and safety.
- Fear of losing an item.
- Boredom, under stimulation.

Strategies:

- Organize, but do not remove, the items.
- Make rummaging an activity. Create "rummage boxes" of safe items the person can sort through.
- Identify the places the person hides things (under cushions, inside shoes, coat pockets, wastebaskets).
- Redirect to another activity.
- Check wastebaskets before you empty them!

Verbal Outbursts

Screaming, yelling, cursing, etc.

Most common in later stage dementia.

Cause(s):

- Pain (studies suggest that 50% of verbal outbursts may be due to pain)
- Medication interaction
- Loneliness, boredom, need something.

Strategies:

- Physical evaluation.
  - A new occurrence of verbally disruptive behavior in a patient with dementia may be the main presenting symptom for many acute conditions such as pneumonia, urinary tract infection, arthritis, pain, angina, constipation, or poorly controlled diabetes mellitus. (McGinn, 2005.)
- Is it something in the environment? Caregiver interaction?
- Quiet music, lollipop

Physical Aggression

Causes:

- Prior personality?
- Pain, physical discomfort?
- Biological – disinhibition, loss of emotional control
- Misunderstanding caregiver actions (esp. personal care)
- Feeling threatened.

Strategies:

- Stay calm. Try not to show fear or anxiety.
- Do not shout or initiate physical contact.
- Reassure.
- Make eye contact.
- Distract.
- Try to identify a trigger.

Paranoia
(suspicion, jealousy, accusations)

Causes:
- Sensory deficits
- Memory loss
- Unfamiliar environment
- Misperception of environment

Strategies:
- Help them look for lost item, then distract to another activity.
- Respond to the feeling behind the behavior and reassure the person.
- Distraction
- Keep a log.
- Medication may be helpful in some instances.

Hallucinations

Causes:
- Vision, hearing impairments.
- Lewy body dementia.
- Change in medications.

Strategies:
- Ignore if harmless.
- Don't argue.
- Check hearing aid batteries.

Sleep- Wake Disorders

Causes:
- Sundowning
- Pain
- Hunger
- Side effects of medications
- Disruption of circadian cycle due to brain damage.
- Dietary: caffeine, sugar

Strategies:
- Increase daytime activity, esp. physical exercise.
- Quiet, calm evening hours.
- Medication as last resort (can increase confusion the next day)
- Is bedroom comfortable? Not too hot or too cold.
- Treat potential pain.
- Maintain bedtime and waking routine.
- Light snack before bed.
- Avoid upsetting activities late in the day (ex. bathing)

Sundowning
(late afternoon or evening)

Causes:
- Changes in circadian rhythm.
- Fatigue is a common trigger.

Strategies:
- Stick to a schedule and routine.
- Turn lights on before it gets dark.
- Close curtains.
- Minimize stress, quiet music.
- Large meal at lunch instead of dinner.
- Keep a journal.

Resistance to Personal Care

Causes:
- Short term memory loss.
- Embarrassment, fear.

Strategies:
- Stick to familiar routine.
- Respect modesty.
- Use dry shampoo for hair washing.
- Towel or bed bath as alternative.

Inappropriate Sexual Behavior

Causes:
- Caused by the disease – reduced inhibitions.
- Uncomfortable clothing – too hot, too tight.
- Pain – UTI, vaginitis, constipation.
- Mistake caregiver for partner.

Strategies:
- Comfortable clothing.
- Distract, redirect.
- Keep a journal to determine triggers.
- Evidence to support pharmacologic interventions is limited.

WHO HAS TO CHANGE? WE DO!

The behaviors you see in dementia are due to a brain disease.

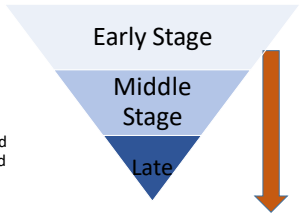
Trying to change or control behavior will meet with resistance.

★ ***Accommodate the behavior, not control the behavior.***
- For example, if the person insists on sleeping on the floor, place a mattress on the floor to make him more comfortable.

★ ***We can change our behavior or the physical environment.***
- Changing our own behavior will often result in a change in the person with dementia's behavior.

Task

- Too complicated
- Too many steps
- Unfamiliar
- Not modified for increased impairment



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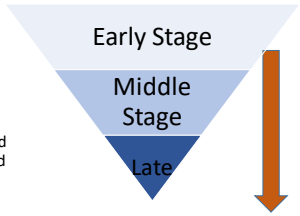

Environmental Considerations

Dementia alters visual perception as well as intellectual functions.

People with the disease may be unable to shut out extraneous stimuli.

Both under- and over-stimulating environments can increase confusion and trigger problem behaviors.

Maximizing Location & Function

Environmental cues:
Ex. Pictures on door

Familiar textures for matching.
Ex. On the seat for meals.

Lighting.

Contrasting colors.

Reduce unnecessary stimuli.

Example of a Residence for Adults with ID

Lack of color contrasts, significant shadowing, and glare increase likelihood of difficulty functioning for the adult with ID and dementia.

Example of Program or Senior Activity Center

Key Concept in Dementia Care #3

Validation Approach

- Focuses on **empathy and understanding**.
- Based on the general principle of ***validation***…the acceptance of the reality and personal truth of a person's experience… no matter how confused.
- Can **reduce stress, agitation, and need for medication** to manage behavioral challenges.
- Forcing a person with dementia to accept aspects of reality that he or she cannot comprehend is cruel.
- Emotions have more validity then the logic that leads to them.

Key Concept in Dementia Care #4

To Reorient or Not Reorient

- Best practice in dementia care: Do not correct or try to "reorient" the person.
- Requires staff to shift their care philosophy…

Example:

"What time is my mother coming?" (You know Ken's mother died 20 years ago.)

Which response is better:

a. *"Your mother is dead, Ken. Your sister will pick you up at 4:00."*
b. *"She'll be here in a little while. Let's get a dish of ice cream while we wait."*

Resources

- National Task Group on Intellectual Disabilities and Dementia Practices
  - Information: *My Thinker's Not Working* https://aadmd.org/ntg/thinker
  - Practices: *Guidelines for Structuring Community Care and Supports for People with Intellectual Disabilities Affected by Dementia* https://aadmd.org/sites/default/files/NTG-communitycareguidelines-Final.pdf
  - Screening: *NTG-EDSD Screening Instrument* https://ucedd.georgetown.edu/DDA/documents/NTG-EDSD-ElectronicForm.pdf
  - Training Workshops: https://aadmd.org/ntg/schedule

We hope we have given you ideas so you can make a difference!

- Remember the basic essence of each person.
- Find laughter and joy each day, there are gifts within the disease and the essence of each person.

"To the world you may be one person; but to one person you may be the world." ***Dr. Seuss***